

Secretary Bowen Sets Department-wide Pediatric HIV Disease Initiative

HHS Secretary Otis R. Bowen, MD, has established a special Departmental Initiative on Pediatric HIV Disease and charged its work group to ensure that efforts throughout the Department are focused on providing the best possible medical responses to the disease as well as the best use of social programs to properly serve the needs of the infected children and their families.

"Children with AIDS have a particular dependency—in many cases, virtually total dependency—on the community and on government. Because of their health care needs and the high costs of treatment; because of the stigma which they, like others with AIDS, often face; because of the fragility of their families and the poverty into which they are often born—for these and other reasons, children with AIDS make a special claim on us.

"Government, communities and individuals all need to respond. By taking steps now, we can better serve children with HIV disease as their numbers grow in future years," Secretary Bowen said.

At present, the number of children with AIDS is relatively small. About 820 younger than 12 years and about 200 aged 13 to 18 years have been reported with AIDS since 1981 in the United States. About 61 percent of these have died. By 1991 there could be more than 3,000 children with AIDS in this country. This estimate reflects only those children with so-called full-blown AIDS symptoms. Another estimated 10,000 to 20,000 children are infected by the human immunodeficiency virus but are either asymptomatic, or are in an earlier stage called AIDS-Related Complex (ARC), with symptoms that may not correspond with the syndrome as it is generally understood in adults, he said.

At present, most cases of pediatric HIV disease are concentrated in three cities, Newark, New York, and Miami, but are increasing in numbers in other cities. About 76 percent of the reported cases resulted from perinatal infection from an infected mother.

About 73 percent of the children with perinatally acquired disease had mothers who were intravenous drug users or were their sexual partners.

The work group also is concerned with children infected because of blood transfusions or because they received contaminated blood products in treatment for hemophilia prior to routine HIV screening of donated blood.

Secretary Bowen noted the special problems pediatric HIV infection poses. Among them are:

- AIDS in children often points to AIDS in families. Children with AIDS are typically from poor, fragmented families whose parents are often drug abusers, infected themselves, and sometimes incapable of caring for the child. There is a great need for services, including foster care, visiting nurses or homemakers, day care and nutrition services, as well as income maintenance and health care itself. Many of these services are supported through HHS programs, and we must ensure that the services are available when needed. We must take down any barriers which might prevent individuals and others in the private sector from providing help.

- At the same time, the natural history of the disease is different in children and less well understood than in adults. We are still learning about the extent to which HIV infection in children may lead to conditions other than those typically associated with AIDS in adults, as for example, effects on the central nervous system and subsequent developmental disabilities.

These differences point to the need for a distinct medical research agenda for pediatric HIV infection, and that is being pursued. But we need to focus as well on nonmedical areas. We need to be alert to any instances where our program rules, definitions, and eligibility criteria may have been designed for other conditions and may require adjustment if we are properly to serve the HIV-infected child, he said.

The pediatric HIV initiative is being organized under an interdepartmental work group announced February 26, 1988. Assistant Secretary for Health

Robert E. Windom, MD, is coordinating the departmentwide initiative. It is chaired by Dr. Antonia C. Novello, Deputy Director of the National Institute of Child Health and Human Development, National Institutes of Health. The Senior Science Advisor to the work group is the Surgeon General, C. Everett Koop, MD. The Deputy Chairperson is John C. Petricciani, MD, Deputy AIDS Coordinator for the Public Health Service. The Executive Secretary is Mary M. Evert, Executive Assistant to the Administrator, HRSA.

The report, issued last year by the Surgeon General's Workshop on Children with HIV Infection and Their Families, provides the framework for the initiative. That conference dealt with the full range of issues surrounding pediatric AIDS and defined the task. A report with recommendations is expected to be submitted to the Secretary by August 30. The report will assess what each HHS agency is doing with relation to pediatric HIV infection, locate research areas not being covered, and suggest future directions for HHS programs.

Secretary Bowen noted that components of HHS have been taking steps to address the special problems of HIV disease.

- The Health Resources and Services Administration is expanding its demonstration projects on innovative caregiving alternatives for those with AIDS. HRSA will seek new proposals to demonstrate models for care for pediatric AIDS, with about \$4.4 million available this year for 10 to 20 grants.

- The Office for Human Development Services has named pediatric AIDS as a high-priority area for child welfare and developmental disability grants. HDS will fund projects to improve recruiting foster parents, and to provide supportive services for natural and foster families.

- The Assistant Secretary for Planning and Evaluation is completing a study of the availability of social services, looking at the experiences of families, health care providers, and social service workers.

- The National Institute on Drug

Abuse is undertaking a public information and education campaign aimed at the AIDS-related problems of intravenous drug abusers. The AIDS information campaign managed by the Centers for Disease Control has targeted youth, minorities, and drug abusers as special audiences to be reached.

The National Institutes of Health has initiated a major treatment effort for children with AIDS, and is supporting projects in pediatric AIDS across the country.

Communities and individuals have provided leadership in helping children with HIV disease. Physicians and nurses in the hardest-hit cities have performed heroically. Individuals who have provided foster care deserve our thanks. We will need many more like them in the future who can offer their time and talents to help lighten the lives of the infected children. Under the initiative, HHS will review regulations to eliminate obstacles or barriers to eligibility and benefits, develop a coordinated research and demonstration agenda to support innovations in service delivery and care for children with HIV disease, provide technical assistance to communities and institutions in order to help families access existing resources, and explore prevention strategies to minimize virus transmission from HIV-infected mothers to their children.

Children with diseases brought on by the AIDS virus need and deserve all of the caring, all the human contact, and all the opportunities for growth that we can give them, Secretary Bowen said.

Issues Related to Care of AIDS Patients Addressed by Task Force Report

Convened by Robert E. Windom, MD, Assistant Secretary for Health, to examine the health care delivery issues involved in providing health care to people infected with human immunodeficiency virus (HIV), an interdepartmental task force completed a yearlong effort by issuing its final report January 6, 1988.

The "Report of the Intragovernmental Task Force on AIDS Health Care Delivery" "resulted in identification of areas which need additional attention and consideration," Dr.

Windom said in a letter accepting the report. "The 17 recommendations in this report address specific issues related to access to care, quality of care, financing of care, integration of government (programs) at all levels, and the role of social support systems."

It is estimated that in fiscal year 1988, the Federal Government will spend \$1 billion on AIDS, including about \$400 million for patient care and treatment (excluding screening), according to the report of the task force directed by David N. Sundwall, MD, Administrator of the Health Resources and Services Administration, a Public Health Service agency. By 1991, direct medical care expenditures for AIDS patients have been projected by the Health Care Financing Administration to range from \$8 billion to \$16 billion. "This means," the report notes, "that a wide variety of organizations will be required to be involved in the war against AIDS. Although this widespread involvement is good, evidence also suggests that there is a lack of collaboration among private sector organizations and a need for technical assistance and information exchange at the Federal level. Such coordination is crucial in order to address gaps in current health care delivery systems and in order to develop alternatives to hospitalization for AIDS patients."

In its findings, the report calls for improvement in

- education, training, and experience of physicians and other health professionals in caring for and counseling persons with AIDS and human immunodeficiency virus (HIV) infection;
- intravenous drug abuse treatment programs;
- recognition of mental illness, psychological impairment, and lifestyle and drug abuse problems in the treatment of AIDS patients;
- nonmedical and nonacute care support services for pediatric and adult AIDS and HIV-infected patients and their families;
- alternatives to hospitalization, such as hospice and home care, intermediate and long-term care facilities, residential and group homes;
- financing programs to cover the particular needs of AIDS and HIV-infected patients;

- voluntary and private sector organizations attuned to the needs and potential for making a significant contribution in the fight against AIDS; and

- health and mental health services research which focuses on the costs, delivery, and effectiveness of services to AIDS patients.

Black and Hispanics are over-represented among AIDS patients, have higher rates of poverty, and are more likely than nonminorities to have no health insurance or to be under-insured, the report continues. Many minorities live in concentrated urban areas where the health care delivery system is already over-stressed. Addressing gaps in services for minorities with AIDS and HIV infection requires targeted local programs that focus on persons with AIDS and HIV infection and their families, as well as the often overburdened institutions that serve them.

The 67-page report also contains 17 major recommendations which call for:

- improving the education of health professionals in the diagnosis, care, and counseling of HIV-infected persons;
- enhancing AIDS training of health personnel in federally supported health facilities;
- providing clinical guidelines to health professionals by wide distribution of a task force-prepared document, "Evaluation of Adult Patients Infected with the Human Immunodeficiency Virus";
- developing innovative methods of caring for intravenous drug abusers;
- developing new approaches for recognizing and treating the mental health needs of persons with AIDS and HIV infection;
- encouraging medical day care and foster care for adult and pediatric AIDS patients;
- encouraging expansion of intermediate- and long-term care facilities devoted to care of AIDS patients through the Department of Housing and Urban Development 232 program (loan insurance for intermediate- and long-term care facilities);
- developing policies and procedures to minimize discrimination and ensure confidentiality in all aspects of the management of AIDS patients;
- funding significantly expanded health services research related to

AIDS and HIV-infected persons;
—encouraging efforts to increase volunteerism in support of AIDS patients;
—convening a national conference focusing on the availability and adequacy of health insurance related to AIDS and HIV infection;
—developing a model educational program for use in the public and private sectors on AIDS in the workplace;
—continuing to examine Medicare and Medicaid policies related to reimbursement for AIDS patients;
—studying the feasibility of developing AIDS-specific diagnostic related groups.
—reviewing hospice regulations under Medicare and Medicaid;
—meeting with State Medicaid directors to explore collaborative efforts related to health care needs of AIDS patients; and
—considering reimbursement by State Medicaid programs and private insurers for necessary AIDS medical therapies.

Represented on the 14-member task force, which was established in January 1987, were senior officials of the Department of Health and Human Services, Department of Defense, Department of State, Department of Housing and Urban Development, and the Veterans Administration.

Copies of the "Report of the Intra-governmental Task Force on AIDS Health Care Delivery" may be obtained from the task force's executive director, Judith B. Braslow, room 9-13, Parklawn Bldg., 5600 Fishers Lane, Rockville, MD 20857, telephone (301) 443-6745.

—FRANK SIS, *Health Resources and Services Administration*

AIDS Patients Eligible for Benefits Under New Social Security Regulation

Low-income persons with AIDS now are eligible to receive immediate financial assistance under the Supplemental Security Income and Medicaid programs.

Under the final regulation published February 9, 1988, Social Security offices nationwide have the authority to make an immediate "presumptive"

finding of disability when there is a confirmed diagnosis that the individual has an advanced stage of AIDS and other factors of eligibility are met. The regulation replaces interim rules operating since 1985.

Based on this "presumptive" decision, the individual may receive SSI payments for up to 3 months and also may be eligible for immediate health care benefits under the Medicaid program without awaiting a formal disability decision. The formal decision is made later, when complete medical documentation is obtained.

"While persons with AIDS must deal with the pain and suffering of the devastating disease," HHS Secretary Otis R. Bowen, MD, said, "this final regulation will assure that when immediate financial and medical assistance is required, it will be provided promptly and with compassion."

Local Social Security offices are authorized to make "presumptive" disability decisions for a limited number of disabling conditions in which there is near certainty that the individual will be found eligible for SSI benefits.

Under the existing interim regulation, the Social Security Administration already makes "presumptive" findings for qualified AIDS patients applying for SSI benefits. The final regulation reflects additional criteria for identifying and documenting AIDS.

SSI is a Federal program administered by the Social Security Administration that pays monthly benefits to about 4 million individuals who are aged, blind, or disabled, and who have limited income and resources—including 3,200 who have AIDS.

Medicaid is the State and Federal health financing program for low-income Americans. Total Medicaid spending for AIDS patients is expected to be more than \$650 million this fiscal year. Medicaid serves about 40 percent of all AIDS patients at some point in the course of the disease. Currently, the Medicaid program pays for nearly one-fourth of the medical care costs of AIDS patients.

Bibliography Available on AIDS Health Services Delivery and Costs

A recent annotated bibliography focuses on the costs and use of health services by patients with acquired immunodeficiency syndrome (AIDS).

The 112-page work lists books, journal articles, and periodicals on health services delivery aspects of AIDS. More than 300 citations are provided on such topics as coverage by private and public programs; aspects of care provided by hospitals and community services, and their costs; and policy issues, projections, and trends.

Citations were compiled from journals and other periodicals in health economics, science, and medicine; technical reports; newspapers and general audience periodicals; and public policy documents. The content of the bibliography was selected for relevance to health services research rather than comprehensiveness. Sections deal with, for example, classification and definition of the disease, community services, drug treatment and vaccines, epidemiology, patient care and treatment, prevention, health insurance and Medicaid coverage, Federal policy, and State activities on AIDS.

"Selected Bibliography on AIDS for Health Services Research" was published by the National Center for Health Services Research (NCHSR) a component of the Public Health Service.

Single copies are available by request from NCHSR, 18-12 Parklawn Bldg., Rockville, MD 20857; tel. (301) 443-4100.